International Journal of Nursing Studies 56 (2016) 17–26

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns

# Effect of integrated caregiver support on caregiver burden for people taking care of people with cancer at the end of life: A cohort and quasi-experimental clinical trial

Kwo-Chen Lee [a,1], Jia-Jean Yiin [b,2], Yann-Fen Chao [c,*]

[a] Department of Nursing, China Medical University Hospital, No. 91, Hsueh-Shih Road, Taichung 40402 Taiwan
[b] Department of Neurosurgery, Neurological Institute, Taichung Veteran General Hospital, No. 1650, Taiwan Boulevard, Sect. 4, Taichung 40705, Taiwan
[c] Department of Nursing, Mackay Medical College, No. 46, Sec. 3, Jhong-Jheng Rd, Sanzhi Dist., New Taipei City 252, Taiwan

ARTICLE INFO

*Article history:*
Received 12 August 2015
Received in revised form 24 December 2015
Accepted 5 January 2016

*Keywords:*
Caregiver burden
Caregiver support
End of life
People with cancer

ABSTRACT

*Background:* Previous studies have shown small-to-medium effects of support on reducing the caregiver burden for advanced cancer patients. A dearth of studies utilized longitudinal design to examine and evaluate the effect of support for the caregiving burden till the patient's death.
*Objectives:* To test the ability of an integrative intervention program for caregivers of advanced cancer patients to lower caregiving burden as death approaches.
*Design:* A two-group comparative design with repeated measures.
*Setting:* Two cancer wards of a single university hospital.
*Participants:* Advanced cancer patients ($N = 81$) and their caregivers were allocated into two groups: an experimental group ($N = 40$) receiving coping strategies, assistance, recourses, and education intervention and a control group ($N = 41$) receiving standard care.
*Methods:* Caregivers received training in the caregiver support intervention at least 3 times every 2 weeks to help them reduce their caregiving burden. Subjective (Caregiver Reaction Assessment) and objective (Heart Rate Variability) measures of caregiver burden were evaluated for caregivers of patients approaching death. Only data within 3 months before the patients' death were analyzed.
*Results:* Caregiver self-efficacy significantly increased and the subjective caregiving burden significantly decreased in the experimental group as patients' death approached. Heart Rate Variability also indicated a calming effect of the intervention, helping caregivers face patients' death.
*Conclusions:* The caregiver support intervention can increase caregiver self-efficacy and reduce the subjective caregiving burden. Heart Rate Variability parameters have the potential to be useful for monitoring caregiver burden in facing patients' death.
© 2016 Elsevier Ltd. All rights reserved.

* Corresponding author. Tel.: +886 2636 0303x1310; fax: +886 2 2636 1267.
*E-mail addresses:* rubylee@mail.cmu.edu.tw (K.-C. Lee), jackson4380@gmail.com (J.-J. Yiin), yfchao.tw@yahoo.com.tw (Y.-F. Chao).
[1] Tel.: +886 4 22053366x7102; fax: +886 4 22053748.
[2] Tel.: +886 4 23592525x5082; fax: +886 4 23741218.

http://dx.doi.org/10.1016/j.ijnurstu.2016.01.002
0020-7489/© 2016 Elsevier Ltd. All rights reserved.

**What is already known about the topic?**

- Since 1995, the World Health Organization Quality of Life (WHOQOL) group has recommended to provide support to caregivers of cancer patients.
- Previous studies with various intensity and duration of support have shown small-to-medium effects on reducing caregivers' burden for advanced-stage cancer patients.
- A dearth of studies evaluated the use of multiple measurements and assessed the benefits of caregiver support interventions in the last 3 months before patient's death.

**What this paper adds**

- Caregiver support programs need to be implemented from the initial to the terminal stage of cancer and reassessed frequently to ensure that the support interventions remain appropriate.
- Our CARE intervention is an appropriate strategy for supporting caregivers in the last three months of a patient's life.
- HRV parameters have the potential to be a useful tool to monitor caregivers' self-efficacy when facing the death of a patient.

## 1. Introduction

As death approaches and symptoms deteriorate, the dependence on others to perform activities of daily living increases in advanced cancer patients. Family caregivers are an important support during the terminal stages of the disease. Taking care of advanced cancer patients can be extremely challenging, with heavy responsibilities associated with managing the patients' symptoms (Weibull et al., 2008), providing emotional support (McPherson et al., 2007), assisting in various care-related tasks (Stenberg et al., 2010), and lending financial support (Pagano et al., 2014). The heavy and diverse work of caring affects the physical (Tomarken et al., 2008), emotional (Doorenbos et al., 2007), social (Kalnins, 2006), and financial (Hanratty et al., 2007) health of caregivers.

Caregiver burden refers to the physiological, psychological, social, economic, and emotional strains that a caregiver experiences while providing continuous care to patients or family members (Given et al., 1992). Caregiver burden is influenced by the characteristics of the patient (i.e., diagnosis, treatment, stage of disease, and functional status) (Ferris et al., 2009; Given et al., 2011), caregiver (i.e., psychological resources and social support) (Lee et al., 2013), and care environment (i.e., socioeconomic status) (Stenberg et al., 2010; Williams and McCorkle, 2011). Objective burden, represented by disruption of the family life, is potentially measureable by observing specific caring tasks; in contrast, subjective burden is difficult to assess because it is related to the caregivers' experiences of physical, emotional, social, and economic difficulties (Montgomery et al., 1985). However, caregivers often ignore or hide their feelings and needs when their loved one is in the terminally ill stage (Raveis et al., 1998). Therefore, tools that can help health care providers identify these difficulties are required.

Self-efficacy is the extent or strength of one's belief in one's own ability to complete a given task or reach a goal, as well as a mediator of health behavior (Bandura, 1977). Self-efficacy can be observed in the coping behaviors that occur in response to appraisal of the caregiving situation. Caregivers facing the stress and challenge of caregiving can benefit from strong self-efficacy. Steffen et al. (2002) indicated that the self-efficacy of caregivers comprises responding to disruptive patient behavior, obtaining respite, and controlling upsetting thoughts. Thus, the ability to identify stressors and increase self-efficacy is central to improving caregiving experiences.

Caregiver burden accumulates through constant exposure to caregiving demands and can affect caregivers' well-being through decreasing physical health (i.e., dysregulated inflammatory control) (Rohleder et al., 2009) and concentration (Mackenzie et al., 2007) as well as increasing mortality (Boyle et al., 2011). A previous study focused on developing and testing interventions to support caregivers through psychoeducation, skills training, and therapeutic counseling (Northouse et al., 2010). However, most of these interventions were delivered in a dyadic manner, and their intensity and duration varied tremendously, resulting in small-to-medium effects on reducing the caregiver burden and increasing caregiver self-efficacy (Lorenz et al., 2008; Northouse et al., 2010). Moreover, few studies have focused on caregivers of terminally ill cancer patients (Kanter et al., 2014; Porter et al., 2011), who might benefit from short visit intervals (Porter et al., 2011) and use of multiple assessment tools (Carter, 2002; Carter and Chang, 2000; DuBenske et al., 2014). Most importantly, the caregiving burden may change rapidly because the physical condition of terminally ill cancer patients deteriorates quickly; however, few studies have used longitudinal designs to examine the caregiving burden till the patient's death (DuBenske et al., 2014). Therefore, we evaluated a support intervention for caregivers of terminally ill cancer patients in Taiwan. We used multiple measurements to assess the benefits of this intervention for caregivers in the 3 months before the patients' death.

## 2. Method

### 2.1. Study design and sample

The study employed a longitudinal repeated-measure design. Caregivers scheduled to receive support intervention sessions at a medical university hospital in North Taiwan between November 2008 and December 2010 were included in this study. The research ethics committees of the study site approved the research protocol (TMUH-05-08-12). Participants were recruited from a cohort of caregivers of advanced cancer patients in two cancer wards at out hospital. The inclusion criteria were as follows: (1) caregivers having a relative with terminal cancer with a survival time of less than 3 months, as judged by the patient's physician and (2) caregivers identified by the patient as the person most involved in the actual care. The exclusion criteria were as follows: (1) patients

Download English Version:

https://daneshyari.com/en/article/1075997

Download Persian Version:

https://daneshyari.com/article/1075997

Daneshyari.com